

How Nurses Can Best Support Families of a Child with Autism Spectrum Disorder: A Model Educational Module for BSN Students

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Abstract

Autism spectrum disorder (ASD) is a developmental condition in around 1.8% of children that results in difficulties with social interaction, speech, and nonverbal communication (CDC, 2020). Diagnosis of ASD is stressful for parents and families, yet a review conducted for this project showed nursing textbooks present a disproportional view of ASD, focusing on severe symptoms and limited information on interventions for family support. This project resulted in a model module to educate BSN students on evidence-based best practices in nursing care with families of children with ASD that use the real experiences of families with ASD to engage students. A focused scoping review of the literature to explore research on families of children with ASD revealed that parents often experience stigma related to the diagnosis, have informational and emotional needs during the initial diagnosis, and benefit from connecting with other parents. Interviews with parents of a child with ASD and a young adult with ASD revealed that families can thrive and successfully support their developing child. The research review, along with reviews of websites for specialty centers for ASD, informational websites on ASD, BSN nursing textbooks, and social media were combined with compelling animated content and the voices of parents to create a model module with educational content, a scavenger hunt of an ASD resource, and reinforcement of concepts through a care plan and a skill exercise. The module was reviewed and critiqued by a BSN educator and will be disseminated in a scholarly publication. Additional resources are provided.

Purpose

The purpose of this project was to create a model module to describe nursing care for families of a child with Autism Spectrum Disorder (ASD) that could supplement learning in a Bachelor of Science in Nursing (BSN) course.

Background

ASD is a developmental condition that results in difficulties with social interaction, speech, and nonverbal communication (CDC, 2020). When a child receives this diagnosis, it can create stress for the parents. Nurses are in a unique situation where they can provide education, emotional support, and connect parents to resources related to ASD in their community. Nursing textbooks frequently present a disproportional view of ASD, focusing on severe symptoms and omitting information on interventions for family support. Therefore, there is a need to create a module for use by BSN students to educate them on how to best care for families of children with ASD.

Methods

A focused scoping review, guided by an HSL librarian, was done to identify evidence on the needs of families of children with ASD. Additional reviews of ASD centers, websites specific to ASD, social media pages, and BSN textbooks were conducted to provide the background for the development of the model module content. Consultation with a BSN educator revealed what content should be included in the module. After IRB approval, interviews of parents were conducted, transcribed, and analyzed by themes to further validate the needs of families of children with ASD. In collaboration with a School of Media and Journalism student, the family interview audio was animated to engage students in the personal experience of families. This content was included in a draft module along with educational content, resources,

and learning activities. This draft was reviewed and critiqued with the BSN educator and refined into its final form. A detailed description of each review in terms of methods, results, and summary is included below.

Results

The completed model module begins by displaying learning goals for the student. Then the module provides education of key features and common symptoms of ASD, clarified by example videos. Animated videos of audio from an interview of two parents of a child with autism are displayed to the learner. The animation serves to engage the viewer in the lived experience of a family of a child with ASD. The module also connects the learner with quotes from a mother of a child with ASD and a young adult child with ASD. The limited scoping review of the BSN nursing textbooks, ASD specialty centers, ASD-specific websites, and ASD social media is included. A scavenger hunt of an ASD specialty center website and a case study activity requiring the student to craft a written response and nursing care plan for a family are also included, with an emphasis on person-centered language. After the module, additional resources are displayed and the written reviews are provided as optional learning tools.

Conclusions

There are five points the BSN student is expected to understand after viewing the module. First, the nurse should provide education on ASD and emotional support to families of children with ASD. Nurses should also assist in connecting parents to resources in their community, such as ASD specialty centers or websites. Additionally, students should understand that families experience stigma related to the ASD diagnosis and the resulting need for person-centered language, BSN textbooks present a disproportional view of ASD symptoms and omit

family support interventions, ASD has a spectrum of possible symptom presentations, and parents benefit from social connections with other parents. A description of the structure and content of the model module, along with the supporting resources, will be compiled for publication in a nursing education journal.

Focused Scoping Review of Research on Needs of Families of Children with ASD

Table 1. Theme: Interventions for Parents

Interventions for Parents							
Name of Study	Type of Study	Number of Studies	ASD Child <18	ASD Child >18	Topic	Findings	Other
Quality of life interventions for primary caregivers of children with autism spectrum disorder: a scoping review	Scoping review	21	Yes, 5-9 y/o	N/A	Identifying and describing the quality of life interventions offered to primary caregivers of children with ASD	<ul style="list-style-type: none"> Themes from interventions were: <ul style="list-style-type: none"> Learning about ASD Interventions for CASD (treatment/how to care) Interventions for PCG (parent care giver) (support/how to care) ½ of interventions needed facilitation from persons with ASD 	<ul style="list-style-type: none"> PCG stress begins at diagnosis, they need to learn how to care for needs, they need their mental/physical health cared for <ul style="list-style-type: none"> ASD poor communication, difficult behavior, limited signs of affection cause stress Family collaboration is important
Mental health interventions for parent carers of children with autism spectrum disorder: practice guidelines from a critical interpretive synthesis	Systematic review	23	Yes	N/A	Identifying key qualities of interventions that support the mental health of parent carers	<ul style="list-style-type: none"> Themes of improving the mental health of parents <ul style="list-style-type: none"> Social support with another parent <ul style="list-style-type: none"> Parent groups, reduced isolation, validation Professional stress management/problem-solving training Accurate information about ASD <ul style="list-style-type: none"> What it is, resources/services 	<ul style="list-style-type: none"> 70% of the caretakers were the mother

(CIS) systematic review						<ul style="list-style-type: none"> Strategies by HCP (health care provider) <ul style="list-style-type: none"> Connect to other parents, be knowledgeable about ASD, advocate for parents to find services/resources, provide written materials to be shared, enhance generic problem-solving abilities and self-perspective taking (sense of meaning as carers) 	
Family therapy for autism spectrum disorder	Cochrane systematic review (RCT/quasi RCT)	0	Yes	Yes	Is there evidence for Family Therapy for young people or adults with ASD, family members or both	<ul style="list-style-type: none"> Limited evidence for family therapy because only a few studies are looking at benefits of family therapy, and none compared it to no treatment or another therapy Hypothesized outcomes <ul style="list-style-type: none"> Quality of social interaction, mental health, life, less adverse effects Satisfaction, confidence in coping, health economic outcomes 	

Coping strategies of parents of children with autism spectrum disorder: a systematic review	<ul style="list-style-type: none"> ○ A systematic review (Quantitative studies, research articles, dx with DSM, standardized questionnaire to examine coping) 	11	Yes, 2.36 – 14.10 y/o	N/A	Examining parental coping strategies and their impact on perceived stress and parent quality of life	<ul style="list-style-type: none"> • Coping strategies used <ul style="list-style-type: none"> ○ Mostly avoidance strategies <ul style="list-style-type: none"> ▪ Some other studies didn't support this ○ Less social support seeking strategies <ul style="list-style-type: none"> ▪ Strained relations with family/friends after dx ○ Mothers used more emotional support / social than fathers ○ Low sense of coherence blames themselves when experiencing stressful situations rather than seeking support/self-controlling ○ Problem-focused strategies lower stress and emotion-focused increases stress 	<ul style="list-style-type: none"> • 1388 parents, mainly mothers (77.8%) mean age is 30.7-46.1 • 60-100% married, 30-73.3% employed
A systematic review of training programs for parents of children with autism spectrum disorders: single	Systematic review	11	Yes, 10-112 months	N/A	<ul style="list-style-type: none"> • Explore the effectiveness of interventions to increase parent's ability to support communication and social development in children with ASD <ul style="list-style-type: none"> ○ (Written Protocol): Pivotal response 	<ul style="list-style-type: none"> • Parents can use the intervention strategies correctly with children in a clinical setting short term, but it is uncertain to which degree the parents can extend and use these treatments as the children grow 	<ul style="list-style-type: none"> • Mother was mostly the caretaker implementing intervention

subject contributions					<p>treatment, natural language paradigm, early start Denver model</p> <ul style="list-style-type: none"> ○ Discrete trial teaching, reciprocal imitation training, milieu teaching, joint attention training, parent-implemented augmentative and alternative communication, general case teaching 		
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Table 2. Theme: Interventions for Children

Interventions for Children							
Name of Study	Type of Study	Number of Studies	ASD Child <18	ASD Child >18	Topic	Findings	Other
Broken bridges – new school transitions for students with autism spectrum disorder: A systematic review on difficulties and strategies for success	Systematic Review	27	Yes	N/A	Synthesize difficulties that school transitions pose for students with ASD and their parents/teachers and the strategies used to support students and parents during this time period	<ul style="list-style-type: none"> • Children with ASD struggle with anxiety and increased social pressure • The strongest strategy against this is exposure to the new school before the transition, using visual supports and 	<ul style="list-style-type: none"> • When the parent does not speak the same language as the teacher there is not proper parent advocacy

						<p>social support, and teaching coping strategies through the transition</p> <ul style="list-style-type: none"> • Parents feel overwhelmed with placement decisions and worry for their children's well-being <ul style="list-style-type: none"> ○ Strategies against this include sharing goals with teachers, use of transition binder to clarify steps 	
Effectiveness of interventions to improve social participation, play, leisure, and restricted and repetitive behaviors in people with autism spectrum disorder: A systematic review	Systematic Review	66	N/A	N/A	What interventions improve social interaction, restricted and repetitive behaviors, play performance, and leisure participation for people with ASD	<ul style="list-style-type: none"> ○ Social skills were improved with group-based training programs and not with computer-based interventions ○ Social communication was improved with joint attention strategies and not with parent-mediated, naturalistic, behavioral, developmental, and imitation training 	

						<ul style="list-style-type: none"> Moderate evidence to support behavioral techniques (antecedent manipulation and self-management) can improve restrictive and repetitive behavior 	
Parent-mediated interventions for children with autism spectrum disorder: A systematic review	Systematic review	13	Yes	N/A	Evaluate the effectiveness of parent-mediated interventions on occupational performance of children with ASD	<ul style="list-style-type: none"> Strong evidence that parent-mediated intervention increased the child's attention Moderate evidence for improvement of language scores, expressive language, nonverbal communicational, response to interaction, behavior play, adaptive functioning, ASD symptoms, and social communications 	
Child and parent outcomes following parent intervention for child emotional and behavioral problems in autism spectrum disorder: A systematic review and meta-analysis	Systematic review and meta-analysis	11 (RCT)	Yes	N/A	<ul style="list-style-type: none"> Assess the evidence for the efficacy of behavioral parent interventions for disruptive and hyperactive child behavior 	<ul style="list-style-type: none"> There were favorable effects of behavioral parent interventions on child disruptive behavior, hyperactivity, and parent stress, but 	

					in ASD children	effects on parent efficacy are less clear	
Communication interventions for autism spectrum disorder in minimally verbal children	Systematic review	2 (RCT)	Yes (< 12)	N/A	<ul style="list-style-type: none"> Assess effects of communication interventions, alternative and augmentative communication intervention (ACC), and verbally based intervention, focused playtime intervention for ASD in minimally verbal children 	<ul style="list-style-type: none"> Limited evidence that verbal based and AAC interventions improve spoken and non-verbal communication ACC intervention resulted in gains in the frequency of PECS use and verbal/nonverbal initiation but not in expressive vocabulary Both studies showed some gain in verbal/nonverbal communication right after the intervention, but neither had improvements over time 	

Effectiveness of interventions for children with autism spectrum disorder and their parents: A systematic review of family outcomes	Systematic review	34	Yes	N/A	<ul style="list-style-type: none"> Examined effectiveness of occupational therapy interventions for children with ASD and their parents to improve parental stress, self-efficacy, coping, resilience, and family participation in daily life and routines 	<ul style="list-style-type: none"> There was a large amount of evidence to show excessive stress of parents of children with ASD There was limited evidence that interventions improve parental stress, some can increase it There is stronger evidence that center-based interventions can improve parental confidence, competence, and feelings of self-efficacy 	<ul style="list-style-type: none"> Mother was the primary caregiver
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Table 3. Theme: Parent Experiences

Parent Lived Experiences							
Name of Study	Type of Study	Number of Studies	ASD Child <18	ASD Child >18	Topic	Findings	Other
UK parents' experiences of their child receiving a diagnosis of autism spectrum disorder: A systematic review of the qualitative evidence	Systematic review – meta-ethnography	11	Yes	N/A	To appraise and synthesis qualitative research on UK parents' experiences receiving their child's diagnosis of ASD	<ul style="list-style-type: none"> These parents had emotional needs, information needs, and relation needs <ul style="list-style-type: none"> Knowledge about ASD leads to increased feelings of self-efficacy 	<ul style="list-style-type: none"> Fathers were more difficult than mothers to reconcile having a child with ASD <ul style="list-style-type: none"> May respond better to strength-based approach support rather than typical post-diagnostic support

						<p>and competence at diagnosis</p> <ul style="list-style-type: none"> ○ There were reports of professionals dismissing concerns of parents about possible ASD ○ Clinical implications need to include consideration of parent's emotional needs, provision of information, and strong relationships with professionals 	
Autism in Brazil: A systematic review of family challenges and coping strategies	Systematic review	10	Yes	N/A	To describes challenges faced by families with children with ASD and what coping strategies they used	<ul style="list-style-type: none"> ○ Before ASD diagnosis families struggle with identifying the disorder and after they struggle with coping with symptoms and poor resources such as health care and education ○ Restructuring the family around the child's ASD needs causes an emotional and physical toll, especially on mothers <ul style="list-style-type: none"> ○ This can be mitigated with a timely diagnosis, improving ASD knowledge, sharing care plans, and 	

						improving social support networks	
Parents of children with autism spectrum disorder had lower relationship satisfaction than parents of children without a disability with positive cognitive appraisal and social support found to be protective factors	Systematic review and meta-analysis	26	Yes	None	Compare relationship satisfaction in a couple of children with and without ASD	<ul style="list-style-type: none"> Positive cognitive appraisal and social support are protective factors Challenging child behavior and parental stress are risk factors for lower relationship satisfaction 	<ul style="list-style-type: none"> Couple of a child with ASD would benefit from relationship support
Parenting stress through the lens of different clinical groups: A systematic review and meta-analysis	Systematic review and meta-analysis	133	Yes	None	Review of parenting stress and child behavior problems	<ul style="list-style-type: none"> There is higher parental stress for externalizing child behavior problems than internalizing behavior problems There is also higher stress among parents of boys, they have higher rates of externalizing behavior problems 	<ul style="list-style-type: none"> HCP should aim to assess parent stress following treatment for behavior problems
The lived experience of US parents of children with autism spectrum disorders: a systematic review and meta-synthesis	Meta-synthesis of qualitative literature embedded in a systematic review	14	Yes	N/A	To look into the lived experience of parents with a child with ASD	<ul style="list-style-type: none"> Siblings were found to be affected negatively by the amount of time parents spend on the other child with a disability, accessing services was a struggle for parents as well Even though there is strain on the family, the parents were not found at increased risk of divorce HCP can share themes of the study to normalize experiences 	<ul style="list-style-type: none"> The majority of participants were mothers Caucasian and African-American were the most represented ethnicities The majority has an income of at least \$30,000 annually, lived in a two-parent household, and were at least 30 years old

						<ul style="list-style-type: none">○ Emotional stress, adaptation, impact on family, services, stigma, appreciating little things○ Adaptation would found as a necessity to reduce stress○ Services were difficult to locate and access, practitioners need to be knowledgeable of services in the area	
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Table 4. Miscellaneous Studies

Miscellaneous						
Name of Study	Type of Study	Number of Studies	ASD Child <18	ASD Child >18	Topic	Findings
Stigma experienced by families of individuals with intellectual disabilities and autism: A systematic review	Systematic literature review	8	N/A	N/A	What stigma families of children with ASD experience, what consequences the stigma has, and coping mechanisms used	<ul style="list-style-type: none"> • Stigma can be public (attitudes held in society about people with ASD) self-stigma, or associative stigma (family members of the affected person experience stigma) • Most family caregivers experienced associative stigma from the community, other family members, and professionals. • People who experience higher levels of stigma were found to have more anxiety and depression symptoms. • Mothers of children with ASD experienced more stigma, caregiver burden, and emotional burden compared to mothers with children with intellectual disabilities. • Self-compassion and strong social support can help combat the negative consequences of stigma • Stigma can cause family caregivers to have negative internalized emotions related to the challenges of having a child with ASD, and stigma can cause them to fear future discrimination

Children with Autism Spectrum Disorder at a Pediatric Hospital: A Systematic Review of the Literature	Systematic Review of Literature	34	N/A	N/A	Identifying behaviors of children with ASD that are challenging and strategies to address these behaviors	<ul style="list-style-type: none">• The review found that non-compliance, due to high anxiety, hyperactivity, sensory defensiveness, and self-injury were the four challenging behaviors identified in patients with ASD.• Non-compliance (often caused by tantrums) can be avoided with calm, concrete language that avoids sarcasm. Decrease stimulation by closing the door and using distraction• HCP should participate in routines requested by the child and should not interrupt self-stimulatory behaviors. Consulting the parent before the visit can help prepare HCP.• Improving communication by pausing after a question to allow processing can help reduce self-injury
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Methods

The literature review conducted used a modified scoping review structure to identify relevant literature to support the project. Scoping reviews provide a broad overview of a topic and allow for a more general exploration of the literature, rather than focusing on providing answers to a specific question, as in a systematic review (Peterson et al, 2017). This review aimed to examine the extent of research on families with children diagnosed with Autism Spectrum Disorder (ASD). The focus of this review was to determine what type of evidence exists, what phase of ASD the children are in, what are the characteristics of the families from these studies, and what interventions were successful.

The literature review followed the research question: *What research has been done for what families with children diagnosed with ASD need?*

A literature search for studies related to the needs of families with children diagnosed with ASD was conducted. Jamie Conklin, a librarian from the UNC Health Science Library, assisted with generating relevant search terms for the PubMed database. The search terms included MeSH (Medical Subject Headings) terms “autism spectrum disorder” and “family”, as well as the additional terms “autism”, “mothers”, “fathers”, and “siblings”. The search was filtered to only include systematic reviews.

After the literature search was conducted, inclusion and exclusion criteria were established to select studies to be included in the review. First, a title and abstract screening was performed and then later a full-text review, both according to the inclusion criteria established. The studies were included if they were: 1) a systematic or scoping review, 2) written in English, 3) published between 2000 and 2020, 4) included families with children with ASD, 5) focused on defining the mental, emotional, or physical needs of a family of a child with autism or analyzed the efficacy

of interventions to alleviate these needs. Studies were excluded if they were: 1) not a systematic or scoping review, 2) not written in English, 3) not published between 2000 and 2020, 4) did not include a family or child with ASD, 5) focused on the risk of developing Autism or another aspect that was not needs of the family or child with ASD.

Studies selected for a full review were organized into an evidence matrix to organize their topics and main findings. Headings on the evidence matrix included the name of the study, methodology of the study, number of studies included in the review, age of the child with ASD, the topic of the review, main findings, and other pertinent information such as family characteristics.

Results

Two searches yielded 65 articles. 18 studies met the inclusion criteria, and one study was removed for redundancy. From these findings four themes emerged, interventions for parents, interventions for children, parent lived experiences, and miscellaneous such as stigma and needs of health care providers.

Summary

The first theme of the included studies was interventions for parents. One study from this theme revealed that parent stress begins at the initial diagnosis of ASD. Stress results from parents feeling overwhelmed that they need to learn about how to care for their child, what treatments are available, the need to learn about ASD as a diagnosis, and the need for support for parental mental and emotional health. A systematic review showed that parent's mental health can be improved with social support from other parents of children with ASD, receiving

information about ASD and what resources are available, and discussing problem-solving abilities with their health care provider. A study on parental coping strategies revealed that some parents don't seek social support due to strained relations with family and friends after receiving an ASD diagnosis. This study also showed that problem-focused coping strategies, rather than emotional-focused, decrease caregiver stress.

The second theme of the literature was interventions for children with ASD. A study on difficulties with school transitions highlighted that parents of children with ASD feel overwhelmed with the placement options for their child, and children need to be exposed to a new environment before the transition to decrease anxiety. Additionally, when there is a language barrier between the teacher and parent, there is not proper parent advocacy for the child. Several systematic reviews revealed that center-based interventions can improve parental confidence, competence, and feelings of self-efficacy. Additionally, when parents can be involved in the interventions at these centers, it increases the child's attention and leads to improvement in behavior.

The third theme found was parent experience. In these studies, parents expressed a need for increased knowledge about ASD, emotional support, and strong relationships with health care providers, especially at the initial diagnosis. After the initial diagnosis, parents struggle to cope with ASD behaviors, poor health care, and education for their child. Improving social support networks, improving ASD knowledge, and sharing care plans can mitigate the emotional and physical toll the diagnosis has on parents. One systematic review recommended health care providers be familiar with services in the area, as some parents have difficulty accessing information about them, talk to parents about healthy coping mechanisms for stress, and speak to families about stigma related to ASD.

The two studies were labeled as miscellaneous as they did not fit into a prior theme. A systematic review on stigma showed that most families do experience stigma related to their child's ASD diagnosis, and this causes anxiety as well as fear of future discrimination. Strong social support and self-compassion in parents can combat the negative consequences of stigma. One study provided recommendations for health care providers when working with patients with ASD. These recommendations included using calm, concrete language that avoids sarcasm, decreasing stimulation, consulting parents about the child before the appointment, and improving communication by pausing after a question.

Focused Review of ASD Content in BSN Textbooks and Lectures

Table 5. UNC Chapel Hill BSN Program

Textbook	Description of ASD	Nursing Care Plan	Family Support
Psychiatric Nursing, 2 nd Edition, Wolters Kluwer, Mary Ann Boyd & Rebecca Luebbert	<ul style="list-style-type: none"> ASD characterized by persistent impairment in social communication and interaction with others, rigidity, and an intolerance of change and outburst in response to routine changes <ul style="list-style-type: none"> Can have intellectual disability, but may not Repetitive patterns of behaviors, aloof and indifferent to others <ul style="list-style-type: none"> Repetitive arm flapping May have self-injurious behaviors Impairment in communication is severe and impacts verbal and nonverbal – echolalia/literal interpretation of words 	<ul style="list-style-type: none"> Long term care with academic, interpersonal, and social experiences that support their development <ul style="list-style-type: none"> Counseling, home care, medication – care can vary based on adaptive functioning Plan intervention that considers child, family, and community supports Assessment of physical health and psychosocial assessments <ul style="list-style-type: none"> Communication (Eye contact, understanding emotional cues) Behaviors (Agitation, repetitive) Flexibility to routine (Home schedule and agitation signs) Individualize treatment to family, child, social environment Physical safety, need for predictability in routine Mental health intervention Teaching self-care skills that consider adaptive skills/language impairment Important to build on strengths and use positive reinforcement <ul style="list-style-type: none"> Will have low self-esteem if they are 	<ul style="list-style-type: none"> Express frustration and provide support group information Support, education, counseling, self-help referrals <ul style="list-style-type: none"> Interpreting treatment plan, modeling appropriate behavior modification techniques, including parents in the care plan, identifying and resolving loss, coordinating support for parents and sibling

		<p>criticized or implied they “need fixing”</p> <ul style="list-style-type: none"> • Promote interactions <ul style="list-style-type: none"> ○ Patience is needed when learning skills • Ensuring safety <ul style="list-style-type: none"> ○ Structure environment and have predictable routines • Behavioral intervention <ul style="list-style-type: none"> ○ Reduce frequency of inappropriate behavior by structuring environment and visual cues at the end of each activity <ul style="list-style-type: none"> ▪ Protection from aggression ▪ Tailoring activity if behavior is dangerous 	
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Table 6. East Carolina University BSN Program

Textbook	Description of ASD	Nursing Care Plan	Family Support
Foundations of Psychiatric-Mental Health Nursing: A Clinical Approach, Margaret Jordan Halter	<ul style="list-style-type: none"> • Children with Autism typically have lower social functioning <ul style="list-style-type: none"> ○ Withdrawn, sensitive to stimulation, attached to objects, routines/repetitive behaviors 	<ul style="list-style-type: none"> • Nursing interventions <ul style="list-style-type: none"> ○ Diversion activities, protection reinforcement for eye contact and social interaction 	None mentioned

	<ul style="list-style-type: none"> • Nursing Diagnoses <ul style="list-style-type: none"> ○ Self-mutilation ○ Decreased social interaction ○ Decreased verbal communication ○ Disturbed personal identity 	<ul style="list-style-type: none"> ○ Medications: Risperdal and Abilify 	
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Table 7. UNC Wilmington BSN Program

Textbook	Description of ASD	Nursing Care Plan	Family Support
Essentials of Psychiatric Mental Health Nursing by Townsend	<ul style="list-style-type: none"> • ASD is withdrawal into self, early childhood/chronic • Predisposing brain structures, familial association, chromosomal abnormalities • Assessment Data • Impaired social interaction <ul style="list-style-type: none"> ○ Focus on the little interest in others • Impairment in Communication and Imaginative Activity <ul style="list-style-type: none"> ○ Focus on the difficulty with communicating with others • Restricted activities and interests <ul style="list-style-type: none"> ○ Focus on a restrictive diet, stereotyped 	<ul style="list-style-type: none"> • Outcome identification <ul style="list-style-type: none"> ○ Exhibits no self-harm ○ Interacts appropriately with staff ○ Demonstrates trust in the staff ○ Can communicate with staff ○ Demonstrate behaviors that show their begun separation/individualization process • Treatment <ul style="list-style-type: none"> ○ ABA therapy, parenting, social-behavioral modification, psychopharmacology (Risperidone and aripiprazole) 	None mentioned

	body movements/self-harming movements		
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Table 8. UNC Charlotte BSN Program

Textbook	Description of ASD	Nursing Care Plan	Family Support
Essentials of Psychiatric Mental Health Nursing by Townsend	<ul style="list-style-type: none"> Explains DSM classification of Autism Spectrum Disorder of impaired social interaction and communication and restricted activity and interest which may be considered bizarre 	<ul style="list-style-type: none"> Intellectual Disability Nursing Care plan <ul style="list-style-type: none"> Risk for injury, self-care deficit, impaired verbal communication, impaired social interaction Nursing Process <ul style="list-style-type: none"> Assessment Data <ul style="list-style-type: none"> Impaired social interaction <ul style="list-style-type: none"> Focus on the little interest in others Impairment in Communication and Imaginative Activity <ul style="list-style-type: none"> Focus on the difficulty to communicate with others Restricted activities and interests <ul style="list-style-type: none"> Focus on a restrictive diet, stereotyped body movements/self-harming movements Nursing Diagnosis <ul style="list-style-type: none"> Risk for self-injury Impaired social interaction or inability to trust Impaired verbal communication related to withdrawal to self Disturbed personal identity Outcome identification <ul style="list-style-type: none"> Exhibits no self-harm Interacts appropriately with staff Demonstrates trust in the staff Can communicate with staff 	None mentioned

		<ul style="list-style-type: none"> ○ Demonstrate behaviors that show their begun separation/individualization process • Nursing Care plan <ul style="list-style-type: none"> ○ Risk for self-mutilation ○ Impaired social interaction <ul style="list-style-type: none"> ▪ Limited carers to gain trust ○ Impaired verbal communication <ul style="list-style-type: none"> ▪ Seek clarification/anticipate needs ○ Disturbed personal identify <ul style="list-style-type: none"> ▪ Assist them to recognize separateness during self-care 	
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Table 9. The University of South Carolina BSN Program

Textbook	Description of ASD	Nursing Care Plan	Family Support
Content Mastery Series Review Module – ATI Nursing Association NCLEX Prep	<ul style="list-style-type: none"> • ASD is a complex disorder with a genetic origin and a wide spectrum of behaviors affecting communication and interaction with others <ul style="list-style-type: none"> ○ Cognitive and language development are normally delayed – lack of eye contact, repetitive actions, routines ○ Sensory integration dysfunction, sleep disorders, digestive disorders, feeding disorders, allergies • Wide variability in functioning 	None mentioned	None mentioned

	<ul style="list-style-type: none">○ Range from an inability to communicate/perform self-care to the ability to function at near-normal levels		
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Methods

The lecture and textbook information was gathered using convenience sampling of students I knew personally in BSN programs at other universities.

Results

Textbook and lecture materials were obtained from 5 different BSN programs at North and South Carolina Universities, and two of the programs utilized the same textbook.

Summary

All of the materials included that ASD was characterized by deficits in social functioning, communication, and behaviors. Three of the materials included a nursing care plan, and all care plans included diagnoses of “risk for self-injury”, “impaired social interaction”, “impaired verbal communication”, and “disturbed personal identify”. Only the materials from UNC discussed interventions for family support including, education, counseling, self-help referrals, as well as mental health interventions, such as, improving self-care activities and focusing on the strengths of the child. Only materials from UNC and USC mentioned the wide variability in functioning presented in those with ASD. The majority of the textbooks focused on assessment and interventions, including medications, for the behavioral aspects of ASD. None of the materials discussed support for children in school, how ASD is diagnosed, or specifics about treatment options or resources for families. There was little material on ASD from lecture materials.

Focused Review of ASD Specialty Centers**Table 9. ASD Specialty Centers Part 1**

Center Name	Website?	Quality of Description of services?	Opportunities to talk to professionals?	Multiple Locations?	Accessible to illiterate people?
UNC TEACCH	Yes	Detailed descriptions including duration, center availability, and what the services entail	Can contact headquarters by telephone or email for questions. Initial referral/consultation can be done over the phone but all other services are offers at the TEACCH centers	Yes, seven locations in different counties across NC	Website is not accessible to illiterate people, but most services are offered in-person at TEACCH centers, these may be more accessible to illiterate families
The Carolina Center for ABA & Autism Treatment	Yes	The description of services is not very detailed. A brief description of the overview of focused and comprehensive treatment is available, as well as a list of what services are available	You can call the center directly, but to get a referral to services you must submit a google form. Services offered in the clinic or at home, but not over the phone	Yes, 4 locations including Cary, Charlotte, Pineville, and Fayetteville	No, services are offered in person, but to receive these services you must fill out a form
Center for Autism & related disorders (CARD)	Yes	Very detailed descriptions of what services available entail, goals of each program, as well as a description of the type of therapy available and how those processes work/are beneficial	Can contact the main company or each location individually by phone, or can fill out a contact form. If a person does not live near a CARD center they offer clinical travel out to your location to provide remote services	Yes, 235 locations in 27 states	A person would need to be literate to use the website, but services are available in person if they were to call the center

Hands Center for Autism	Yes	Services are listed on the front of the website and include a description of the techniques used and evidence for their success (Applied behavior analysis, early intervention). Must contact via the form to find out more information about these services at a particular center	Can call for a consultation or fill out a form to learn more. But services are offered at the center, not over the phone	One location in Cary, NC	Besides being able to call the center on the phone, the website is not accessible to illiterate people
Duke Autism Clinic	Yes	The website lists the services provided but has no description available about them.	The website provides phone numbers for all doctors that work in the clinic	There is only one Durham location at Duke Hospital	There are phone numbers to call the office and the doctors who work in the clinic, but besides that, the website is not accessible to illiterate people

Table 10. ASD Specialty Centers Part 2.

Center Name	Accessible to non-English speakers?	Bias Present?	Navigation ease?	Connection to other parents?
UNC TEACCH	No non-English options/information on the website	Some images on the website have multiple races shown, but the majority are white children/adults. The administration is all white women.	The website layout made it very easy to look at all of the services provided at once. They are all listed on one page with descriptions underneath the service name. The central menu allows for services available, about, and locations to be found quickly	Discussion and lecture groups are available in group settings at the centers, but there is no connection to other parents on the website alone
The Carolina Center for ABA & Autism Treatment	No non-English options/information on the website	Pictures on the website are all of white children except one. The administration is all white adults	This website is easy to navigate. A central menu allows for only a few clicks to get to a page about services, paying a bill, or about the center	No, there is no connection to other parents via the website, and all services are offered individually for each client and family
Center for Autism & related disorders (CARD)	Yes, there is a section of the website that explains Autism in Spanish and has a link for a Spanish version of the website. Services are available for Spanish speaking families	Pictures on the website showcase people from a variety of races and backgrounds.	This website is easy to navigate. There is a menu with all aspects of the website listed. It only takes one or two clicks to find information on services or contact. There is also an	There is no connection to other parents on the website, and the services are focused on the person with Autism only

			option to visit a Spanish website.	
Hands Center for Autism	No non-English options/information on the website	There are pictures of children from multiple races in the photos across the website, but the administration is all white adults	This website has a bright menu with large options right on the home page about their services, so it only takes a few clicks to find out more about what this center has to offer	The website describes a “parent lounge” at the center where parents can relax and meet other families during their child’s treatment session, but there is no direct connection to other parent's through the website
Duke Autism Clinic	No non-English options or information on the website	The doctors who staff the clinic’s pictures are on the website and there are doctors from various ethnic backgrounds	The website has a menu bar at the top for easy navigation between topics, many categories in each menu selection break down the information	There is no opportunity to connect with other parents via the website and no group services offered

Table 11. ASD Specialty Centers Part 3

Center Name	Profit/Cost and Insurance Information	Social Media/ Yelp Reviews
UNC TEACCH	There is a page for fees that explains that they accept the same insurance providers as UNC Health Care, but there are no exact costs on the site.	No Yelp page available. The Facebook page has 4.8 out of 5 stars based on 70 reviews. Positive reviews praise the staff for being patient and respectful and mention how the training for professionals offers valuable skills. No negative reviews were seen.

The Carolina Center for ABA & Autism Treatment	There is no information on the cost/insurance providers accepted on the website. To be accepted for services you must fill out a form that includes insurance information	The Facebook page had an average rating of 3 out of 5 stars based on 4 reviews. Positive reviews mentioned a positive atmosphere and negative reviews mentioned disagreeing with ABA treatment. There was no yelp page available.
Center for Autism & related disorders (CARD)	There is a section on the website describing how insurance should cover autism services and how to appeal insurance denial. There are no specific costs for services listed on the website, and no information about if the center is for profit or not	The Facebook page for this organization does not allow review and there is no central Yelp page available.
Hands Center for Autism	There is no information on the website about if the center is for profit or not, or specific costs for services. There is a page that explains how the center will work with you to get insurance coverage and lists providers they work with.	No reviews are posted on the organization's Facebook page and there is no Yelp page available.
Duke Autism Clinic	There is no information about if this clinic is for profit or not, costs of services, or insurance provider coverage. You must call to make an appointment to discuss costs/insurance.	Reviews are not allowed on the Facebook page and there are no reviews posted on the Yelp page.

Methods

A google search for “Centers for Autism Spectrum Disorder in North Carolina” was conducted and the resulting websites for the centers were reviewed for themes. Centers were included if they 1) Offered services specifically for ASD, 2) Had a functioning website representing the organization.

Results

The search resulted in 10 websites identified. Eight websites met the search criteria and one result was eliminated for redundancy. A maximum of five centers was chosen because saturation was reached after reviewing five websites.

Summary

Three of the centers had a detailed and quality description of the services they offered. One of the centers did not have a quality description of services, and only the Duke Autism Clinic did not have an accessible description of provided services. All of the centers provided the opportunity to talk to a professional over the phone. All but two of the centers offer multiple locations, with the remaining centers only have one location. All of the center’s websites would not be accessible to illiterate persons, but phone numbers are available. Only the Center for Autism and Related Disorders website offers a non-English version of the website (Spanish), all other resources are only in English. The Center for Autism and Related Disorders and The Duke Autism Clinic display images of people of various races and ethnic backgrounds and have providers of multiple races, but the other centers display a majority of white adults and children. None of these centers offer connections to other parents on their website or information about the cost of services. Lastly, information about all centers would not be accessible to someone without the internet.

Focused Review of ASD Educational Websites**Table 12. ASD Educational Websites**

Website Name	Education? (ASD signs, assessment, recognizing)	Connection to other parents?	Assistance for parents to manage day to day living with ASD children	Social Media/Yelp Reviews
Autism Society of NC	This website has a description of what ASD is and a list of common signs /behaviors. The list of DSM-5 criteria for ASD is listed on the website. There are also recorded webinars that address what to expect after an ASD diagnosis	There is information on the website about parent support groups that one can attend, however, there is no direct connection to other parents on this website in a virtual format	There are many recorded webinars available that cover how to manage behavioral symptoms, IEP services, as well as about adult needs for college and residential options. There are some Spanish options available. There is also a social narrative to help teach concepts to the child	4.6 out of 5 stars based on 33 reviews on their Facebook page. Positive reviews mention strong leadership and a wealth of resources available. Negative reviews mention that they do not agree with the use of applied behavior analysis
Autism Speaks	There is a description for signs of ASD at different ages in a child's development. DSM-5 criteria for ASD are also listed. There is a screening tool for parent use.	There is a resource to help parents to find support groups in their area, but no direct connection to other parents via the website	There is information on finances, safety, school, health/wellness, technology, behavioral issues, medical resources, adulthood, and community life. As well as an adult with autism information and information to support families	Their Facebook page does not allow reviews. On greatnonprofits.org (nonprofit review website) they have a rating of 1.6 out of 5 stars based on 43 reviews. Negative reviews frequently mention that this group's advertising portrays individuals with ASD as frightening and someone that "needs to be fixed", and that most of their money goes towards salaries and advertising rather than for services and resources for families. Negative posts for the organization on the Autism Parents Group on Facebook have similar messages.
Autism Society of America	This website provides a link to the CDC website with signs/symptoms of ASD as well as the CDC page for normal behavioral milestones for children. There is information on early autism signs and the DSM-5	There is no direct connection to other parents on the website, but there is a section called "Stories from the Spectrum" where parent's or children	There are publications available to educate parents on educational success and transitioning grades. There are also online courses about treatment options and transitioning to adulthood. There is not much	4.6 out of 5 stars based on 176 reviews on Facebook. Positive reviews mention that this website helped educate them about autism and provide resources. Negative reviews mention a lack of resources in certain areas of the United States.

	criteria. There is also a page on the importance of early ASD screening, but the link to a screening tool is not functioning	with ASD can submit stories about their own experiences	information that would help day to day problems in the household	
Autism Navigator	This website provides information about what ASD is, early signs, the diagnosis process, and provides tools to help parent's share early signs of ASD with others	There is no direct connection to other parents on the website	There are online courses that provide information about how to deal with s/s of Autism for parent's and videos of what the signs look like in ASD children at different ages	No Facebook or Yelp page available
Autism NOW	This website is an information center for information about ASD and resources for families. It goes over the diagnosis of ASD but no basic information of signs or symptoms is discussed	There is no direct connection to other parents on the website	There are pages with information and resources for many areas of life, home life, getting a job, education/classroom programs, and transition advice	No Facebook or yelp page available
Autism research institute	This website provides information about what ASD is, diagnosis, screening tools, and ongoing assessments for parents	No connection to other parents on the website	There are online webinars to discuss the latest research and information about ASD, but these are offered in real-time throughout the year	No Facebook or Yelp page

Methods

A Google search for “Autism Websites in North Carolina” was conducted. The first two pages of Google were screened for the inclusion criteria and themes, as these websites would be most accessible to others researching Autism Spectrum Disorder.

Results

Websites were included if they: 1) focused mainly on ASD, 2) provided education on some aspect of ASD, 3) provided some information or resources to assist parent's in managing their child's condition. There were 15 websites identified and 6 of these websites met the inclusion criteria for the study. A maximum of 6 websites were included because a saturation of themes was present after reviewing these 6 resources.

Summary

All six websites offered education regarding signs of ASD and DSM-5 criteria for diagnosis of ASD. Five of the websites offered education about normal behavior milestones in children and parental screening tools for children suspected of having ASD. None of these websites offered a direct connection to other parents, but two of the websites offer information about locations of in-person parent support groups. Only the Autism Society of America website has a section where parents and children can submit their experiences with ASD for others to read. All six websites have resources for parents regarding their child's school and how to support a child with ASD's transition to adulthood, but only three websites offered information about managing a child with ASD's daily behavioral issues. Only the Autism Society of North Carolina's website offered information in Spanish, the rest were English-only websites. Two of the three websites had 4.5 out of 5 stars based on reviews from their Facebook pages, and these reviews mention the websites quality resources. Autism Speaks had an average rating of 1.6 out

of 5 stars on greatnonprofits.org, with negative reviews mentioning poor advertising messages and misuse of funds. None of these websites would be accessible to someone without an internet connection.

Focused Review of ASD Social Media

Autism Parents Group

This is a private Facebook group that has ~33,000 members. You must request to join the page. The Autism Parents Group was found by searching “parents’ group for Autism” on Facebook. Once on the page, it is a discussion board where parents or people with ASD can post their experiences or ask questions to the community. This group is tailored towards mothers, but fathers can also be included. Fundraising, self-promotion, or discussions about “curing Autism” are not allowed. A popular type of post on the group describes various behaviors of member’s children, and the poster is typically seeking advice or validation from others. Additionally, many members ask for other’s suggestions of resources

Autism Nutritionist

This is an Instagram page run by Jenny Friedman that offers ideas for how parents of children with ASD can expand their child’s diet and introduce them to new foods. Autism.nutritionist was found by searching “autism food page” on Instagram. This page has 541 posts and also offers a link to a blog with further diet tips.

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